EBP Edge—More Isn't Always Better: Therapy for Children with Lifelong Disabilities, Part 2

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Editor's Note: The following article by Kathy Clapsaddle is the second of a two-part series delving into therapy services for Children with Lifelong Disabilities. TSHA members can apply for .5 hours of ASHA CE credit for each article in the series. The first article can be found here.

Introduction
In the previous article, the case was made for consideration of episodic care as a service delivery framework for medical therapy for children with chronic lifelong disabilities. Episodic care was defined as bursts of treatment to achieve a meaningful achievable participation-based goal in a defined period of time. This was contrasted with continuous care throughout childhood, which may be unsustainable both from a family perspective as well as for the economy as a whole. As healthcare costs are rising and as we have gathered more best practice information, attempts are being made at both the state and federal level to manage the spending for medical services for children. As a result, pediatric medical therapy has begun to shift focus to addressing participation and function, decreasing costs, and increasing the value of therapy services.

While no studies explicitly compare an episodic treatment model to a continuous model, research was reviewed regarding treatment dosage. The evidence did not indicate that continuous services for years on end at a treatment frequency of two sessions per week would lead to better outcomes than another combination of treatment frequency, dose, or total intervention duration. The article contended that treatment provided in episodes around an emergent need may even lead to better quality of life for the child and family and more opportunities for the generalization of skills into home and community environments.

Pulling it All Together: The Role of Caregivers and the Home Program in Episodic Care
For therapy to be optimally effective in an episodic care model, other factors must be considered because of the unique structure of this service delivery model. Episodic care requires that caregivers take a more active, engaged role in intervention due to the nature of therapeutic breaks and dosage variations.This is dependent on the confidence and effectiveness of caregivers to support the therapy plan outside of direct therapy services. If services during an episode of care are truly addressing the child's and family's functional needs, the family must feel empowered to express those needs and advocate for services that address them. As the WHO (2001) stated, the ultimate goal for children and families is participation in their lives outside of therapy. Thus, the main priority for speech-language pathologists (SLPs) should be for children and families to be autonomous, confident, and successful without intervention. Building caregiver confidence and autonomy includes building collaborative relationships with caregivers and ensuring that the prescribed home program is manageable and meets the family's needs.

Therapeutic Relationship
Evidence has emerged on the role of the therapeutic relationship, or the emotional bond between the SLP and the client/family, and its impact on the effectiveness of intervention (Fourie et al, 2011).The relationship that clinicians have with caregivers may be as important as the work they do with the children. Duchan and Kovarsky (2011) argue that clinical rapport has a "central role" in communication during therapy. ASHA's Preferred Practice Patterns (2004) noted that families should be significant partners with SLPs in therapy.

Effects of Therapeutic Relationships
Much of the evidence on therapeutic relationships is in the therapist-client dynamic. A systematic review on these therapeutic relationships found a significant impact on therapy outcomes (Kelley, et al, 2014). Specifically, the researchers divided the components of the relationship into the categories of emotional care, including characteristics like trust, empathy, and cognitive care, including patient education. Additionally, Law (1998) found that respect and collaboration elements of the therapeutic relationship were important predictors of rehabilitation outcome. While much of this work is with adult patients, even pediatric patients reported that their perceptions of positive therapy outcomes were linked to the therapeutic relationship (Duchan and Kovarsky, 2011). However, due to the significant communication impairments experienced by many children with chronic, lifelong disabilities, that relationship may be limited in terms of feedback from the child.

Similarly, there is evidence that working collaboratively with caregivers is key to successful intervention (Ferguson & Armstrong, 2004; Crais, Roy, & Free, 2006; Blackstone, Ruschke, Wilson-Stronks, & Lee, 2011). Evidence suggests that collaboration between caregivers and clinicians may improve both caregiver commitment to goals and engagement in intervention (Diamond, Diamond, & Liddle, 2000). Research by Coogle & Hanline (2016) found that caregivers reported that feeling competent, strong communication with therapists and therapist trustworthiness were important factors in successful intervention. James and Chard (2010) reported that caregivers preferred being treated as an equal by their therapist. A strong therapeutic relationship also may help diminish some of the stress felt by many caregivers of children with lifelong disabilities (Boyd, 2002; Siklos & Kerns, 2006).

Furthermore, an imbalanced family-clinician power dynamic can diminish therapeutic outcomes. Ferguson and Armstrong (2004) found that relationships in which the clinician is seen as a "professional expert" and the client or family is seen as powerless could result in less engagement in therapy and force families into a role of dependency (Fourie et al, 2011). Plexico et al. (2010) found that a focus on therapy alone was damaging to the relationship. Even pediatric clients report the negative feeling of a sense of powerlessness in therapy (Duchan and Kovarsky, 2011).

Considering the impact of the therapeutic relationship on the effect of therapy is important yet is not often overtly considered by many SLPs. However, caregiver-clinician collaboration in therapy appears to be an important part of the success of intervention. SLPs cannot make or force caregivers to be part of their child's therapy. Instead, they must partner and collaborate based on what matters most to the child and family.

Stages of Therapeutic Relationships
Many clinicians struggle with the "how" of the therapeutic relationship. Strong therapeutic relationships are developed over time by skilled clinicians who have an understanding of the process of developing the relationship. Therapeutic relationships develop in stages that can be generally described as beginning, middle, and late. The CONNECT Project, a collaboration between the Frank Porter Graham Center at the University of North Carolina and the University of Kentucky, describes the three stages as being on beginning, middle, and firm ground with caregivers (CONNECT Project, 2016).

Developing an initial friendly relationship, or being on beginning ground, is a stage in which therapists foster comfortable interactions with families. Interactions should be characterized by ease and openness as well as high expectations, respect, commitment, equality, and advocacy (CONNECT Project, 2016; THERAPY 2000, 2016).Making shared decisions, or being on middle ground, allows clinicians and families to have multiple opportunities to interact, exchange information, and share insights with each other in the process of shared decision-making. With the development of trust, conversations and information exchanges are easier and less guarded. This allows for more personal topics to be discussed more candidly (CONNECT Project, 2016; THERAPY 2000). Finally, firm ground relationships allow caregivers and therapists to address challenging issues and develop trusting partnerships. These partnerships enable clinicians and caregivers to

handle difficult problems in a positive and constructive manner. When on firm ground, partnership-oriented communication practices including high expectations, respect, commitment, equality, and advocacy become the most sophisticated.The length of time it takes to reach a firm ground stage of the relationship can vary significantly from one caregiver to another depending on the family's preferred communication style, culture, and preferences, as well as the skill and knowledge of the therapist (CONNECT Project, 2016; THERAPY 2000).

Self-Knowledge Required for Therapeutic Relationships
Therapeutic relationships also require that SLPs have an underlying knowledge of self that contributes to the effectiveness of the relationship. This knowledge includes self-awareness, empathy, and awareness of professional boundaries (RNAO, 2002). Self-awareness is the ability to reflect on one's thoughts, biases, feelings, and actions and to recognize them as subjective (RNAO, 2002; Eckroth-Bucher, 2010). Self-awareness is required to recognize the impact of events and experiences outside of the therapy setting on the way clinicians interact with caregivers. For example, if a clinician is experiencing significant stress in their life, they may appear irritable or preoccupied when engaging with a caregiver. The self-aware clinician recognizes that stress can impact the interaction and may make a conscientious decision to try to focus on the present moment (RNAO, 2002).

Clinicians also should be self-aware of the implicit bias (defined as "implicit stereotypes and prejudices") they bring to encounters with caregivers (FitzGerald and Hurst, 2017; p 2). Multiple systematic reviews found evidence of healthcare provider implicit biases that may influence diagnosis and treatment decisions and even the quality of care provided (FitzGerald and Hurst, 2017; Hall et al, 2015; Dehon et al, 2017). As clinicians are often not aware of these biases, consciously analyzing negative attitudes toward some family and caregiver characteristics, such as poverty, race, or obesity, can help clinicians recommit to equality in these caregiver relationships (FitzGerald and Hurst, 2017). Building self-awareness is not necessarily an easy task; however, some suggestions are present in the literature, including journal writing, self-reflection on one's actions, talking to a friend or mentor, or mindfulness and meditation (Gessler and Ferron, 2012).

Empathy is the ability to put oneself in another's position (Finset & Ørnes, 2017).It requires the SLP to see the world as the caregiver sees it and to "validate that his/her understanding is an accurate reflection" of the caregiver's experience (RNAO, 2002, p.21). That doesn't mean that the clinician must actually feel the same way as the caregiver but that the clinician can understand and value those feelings. Acting empathetically in a way that improves the therapeutic relationship requires the clinician to understand the caregiver's perspective and feelings, clarify and communicate that understanding with the caregiver, and use that understanding to engage with the caregiver in a helpful way (Finset & Ørnes, 2017). Improving empathy requires that clinicians are self-aware of their emotional responses to caregivers. SLPs can ask themselves, "Are my responses compassionate or do they encourage a more surface-level interaction?" (Gerace, 2018). Therapists also can self-reflect on how the experiences in their past may be similar to those of the caregivers, which may help them more easily understand the caregiver and improve their motivation to help them (Gerace, et al, 2015).

Finally, an awareness of professional boundaries helps SLPs define the limits of their role as a professional (RNAO, 2002). Clinicians with a strong awareness of professional boundaries recognize the potential vulnerability of the caregivers they support and "do not exploit their trust and dependency in a way that might compromise the therapeutic relationship" (CRNM, 2019, p. 1). The College of Physical Therapists of British Colombia (2009) notes that power, trust, respect, and closeness are four components of a therapeutic relationship that a therapist must consider when managing the boundaries of the relationship. Violation of any of those four components can be damaging to the relationship. Working closely with caregivers, particularly in home-based care or early intervention settings, can sometimes make it difficult to define those limits and can create opportunities for boundaries to be crossed. Having "special clients," receiving extravagant gifts from caregivers, receiving texts or calls from caregivers about personal issues not related to therapy or

the child, or spending extra time with caregivers of some clients may be indications that boundaries could have been crossed (RNAO, 2002). In order to maintain appropriate professional boundaries, it is recommended that SLPs are clear about boundaries from the initial interaction as caregivers may take their cues for the expectations of the relationship based on the therapist's actions (CPTBC, 2009). Therapists should explain what an SLP does, their role in the overall treatment of the child, and what the clinician and caregiver will do together. Clinicians also should be aware of statements or behaviors that may be uncomfortable for the caregiver and may impact the relationship (CPTBC, 2009).

Home Programs

The home program is another factor that must be considered as part of the episodic framework as it is what persists during a therapeutic break or reduction in treatment frequency. The literature presents strong evidence that home programs can improve therapy outcomes (Fey et al., 2006; Roberts and Kaiser, 2011; Crowe et al., 2004; Allen and Marshall, 2011; Yoder and Warren, 2002; McConachie et al., 2005; Reagon and Higbee, 2009; Novak et al., 2009; Mullen and Schooling, 2010). Research generally indicates that therapy with a home program leads to greater progress toward speech and language goals when compared to therapy provided without a home program.

Further, two systematic reviews suggest that parents may be as effective as therapists when they receive appropriate guidance and teaching from a therapist (Roberts and Kaiser, 2011; Law et al, 2010). In both reviews, there was no significant difference in child progress from clinician-administered intervention versus trained caregiver-administered intervention. Additionally, Novak and Cusick (2006) found that parents will practice skills more often when they identify improvements from a home program. Novak (2012) further suggests that opportunities to practice skills in daily life are just as important as the amount of hands-on therapy received.

Teaching and empowering caregivers requires a unique set of skills. Anecdotally, many clinicians report that these skills are often more challenging and less directly taught either in graduate programs or continuing education opportunities than other clinical skills. However, given the cost constraints on direct therapy services, and the apparent benefit of a home program on the effectiveness of services, clinicians can look to the literature for some guidance on how to create a meaningful home program.

Effective Home Programs

Novak (2011) noted that home programs should be developed in partnership with the caregivers. She found that home programs developed with caregivers were perceived as advantageous and "less demanding" by caregivers than home programs prescribed by therapists alone, because they fit into family routines. Novak (2011) also noted that home programs should be collaborative and co-developed across therapy disciplines. She noted, "Parents described experiencing feelings of 'confusion' and becoming 'overwhelmed' when parents received multiple home programs from multiple professionals. In contrast, parents described that when they received interdisciplinary home programs from 'therapists who worked together,' it was very helpful" (Novak, 2011; p. 208).

Lillo-Navarro et al (2015) found that home programs should fit within a family's daily routines and should be simple. Caregivers reported that adherence to a home program was low when they had difficulty incorporating it into their daily routine, primarily due to difficulty scheduling the activities. Caregivers were more likely to participate in a home program when the program was simple and did not significantly impact life at home. Caregivers also reported that providers often expected "strict adherence" to a home program, but that made it difficult to provide "normal life" for their family (Santer, 2014). Further, caregivers wanted the home program to be fun and make a difference in the child's functioning. They preferred activities that were enjoyable for their children and were less likely to participate when activities were perceived as "too complex," causing pain/discomfort, or not showing change in the child's functioning (Lillo-Navarro et al, 2015; Novak, 2011).

Finally, Lillo-Navarro et al (2015) found that caregivers preferred feedback from providers on implementation of the home program to build their confidence and that they were more likely to continue with the program when they felt like they were "doing it correctly at home" (Lillo-Navarro et al, 2015; p. 84). In addition, too much pressure to participate in the home program was not helpful and could be damaging to the caregiver/parent relationship. Caregivers felt that pressure to "comply" with the home program was counterproductive and typically resulted in the parent not wanting to continue with the therapist (Novak, 2011).

The therapy process may change if therapists consider the home program as an integral part of the intervention, as opposed to something that happens in addition to therapy. Planning for the home program should be done as intentionally as planning for therapy activities, and caregivers should be an active part of that planning process. Decisions made with that framework may lead to more intentional and effective home programming as well as opportunities to continue to build and maintain the therapeutic relationship.

Working with Asher's Caregivers and Home Program
Asher's SLP has been working with him and his caregivers for two years and has worked to develop a relationship with Asher's mother, who was most frequently present during therapy sessions. Prior to therapy with his current therapist, Asher's mother had not been an active part of the therapy sessions. His current SLP gently encouraged her to participate, although she was initially very hesitant. She started with just the last five minutes of the session, and then the SLP began to encourage her to be more involved in every session. She also made a point of talking to Asher's mother each session about how things were going with Asher outside of therapy. The SLP practiced listening more than offering advice as well as confirming her when she tried to do something to support him outside of therapy. She learned that Asher's mother felt that the therapists "knew what to do" and that she felt worried that she would say or do the "wrong thing." Asher's mother and SLP built a strong relationship. By the end of the two years together, Asher's mother reported that she felt more "in control" of what happened with Asher and that she "has learned a whole lot." But most importantly, she felt that "she knows a lot as his mom, and that's what matters the most."

This relationship supported the effectiveness of the home program. Asher's SLP wanted to incorporate his partner-assisted scanning board into routines at home. When she first recommended a home program for Asher, she told the family to try the board to request activities during leisure time after school. Initially, the SLP noticed that his mother did not report that they had practiced using the board. She asked the mother about it, and she gently let the mother know that if it seemed like too much, it wasn't the right program. His mother reported that she didn't use the board after school because he usually was tired and always wanted the same activity—to watch and listen to preferred videos. He was becoming increasingly frustrated with caregivers when using the board during his afterschool routine. The SLP then worked with the caregivers to determine which routine would work best for practicing using the board. They determined that weekend leisure time would be better and that his caregivers could make the decision as to which time of day would be best based on how he was feeling. The SLP noticed that the caregivers reported using the board with more frequency, particularly after his mother reported that Asher was "excited" when she understood that he wanted a different video. His mother also independently started using the board during his bath and bedtime routine.

Conclusion
Considering therapy through an episodic model, while incorporating dosage variations and/or breaks in direct service, may lead to greater life participation for children and families. It is well established that families of children with disabilities experience increased stress (Hsiao, 2017), and anyone with children knows that meeting the daily scheduling requirements of life with children can contribute to that stress. If families are waiting at home or in a clinic for therapy services, caregivers are not able to "catch up" on the things in the home that life with children demands of them. Children are not able to decompress after long, taxing days at school. And perhaps most importantly, children are not engaging with peers and siblings in a meaningful, self-directed way.

While therapy provides an incredibly valuable role in promoting development of a child's skills, there is also value in providing opportunities for all children to just be children. If clinicians truly develop an intervention plan with the intent of supporting autonomy in caregivers and children, would the therapy plan not only include interventions to support the child's independence but also plans and supports to accommodate the child's current skills in their life at home and in the community? Can we better view the children we serve through not only the lens of a child with a disability who needs treatment but also as a child within a greater family structure in their community as a whole?

Additionally, it is clear that working collaboratively with families and supporting them through development and implementation of a meaningful home program can potentially have significant positive impacts on therapy outcomes. When families are engaged in the therapeutic process and have a voice in the development and focus of the home program, they are more likely to follow through with the program. Episodic care works when caregivers agree with the plan. When caregivers feel confident and successful as home program collaborators, they are more likely to feel comfortable and safe during periods without direct therapist intervention.

Finally, treatment plans should be made in an individualized way through true collaboration with caregivers at all stages of intervention. Clinicians should stop each time a treatment plan is developed and consider what factors are in play that are impacting the decisions within: Has research on dosage been considered, or is the dosage determination simply in line with what other children receive? Has the family been part of the dosage decision-making process? Does the treatment plan truly revolve around the participation needs and goals of the family, or is it more focused around deficits identified on standardized testing? Has the family's schedule, readiness for intervention, and ability to be part of the treatment plan been considered?

Collaborating and partnering with caregivers is not natural, nor easy, for all clinicians. While it may seem intuitive for some, it is in actuality a set of skills that SLPs must develop and hone over the course of their careers. Saying that a plan was developed collaboratively and actually having the skill to engage the caregiver in a meaningful way to give them confidence and comfort in helping to develop the plan may be two separate things. Clinicians often report difficulty in getting information or participation from caregivers in this process. We must be self-aware enough to realize that our own behaviors, communication, feelings, or biases may be, at least in part, responsible for that difficulty. Introspection may be required for SLPs to truly make professional gains in building therapeutic relationships, but the outcome of that work may be life-changing for the families we serve.

Truly sustainable care, at the child level as well as the industry level, requires that we take a hard look at what we do and why we do it. SLPs can either worry about the ever-increasing costs and regulatory burden and decreasing reimbursement rates, or they can re-think what those services and relationships look like in a way that still makes significant improvements in the child's skills—and may actually be better for families.

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